Thank you for the privilege of sharing in this conversation.

- Norma J. Hirsch, MD practicing physician in Iowa for 26 years
- Currently serve as medical staff affairs coordinator and hospice physician for Hospice of Central Iowa
- Today I speak as a member/representative of the Iowa Medical Society and as a member of the Board of Directors of the Iowa Hospice Organization

GENERAL RESPONSES TO TERRI SCHIAVO SCENARIO:

- There are many misunderstandings about the administration/withholding of food, fluids, and nutrition. In terminally ill patients with life altering diseases, it is the patient's disease, not the decision to withhold/withdraw food, fluids, and nutrition that ultimately leads to the patient's death.
- I believe that reframing the cultural implications of food is essential if we are to assist people in making a more informed decision about withholding/withdrawing food, fluids and nutrition. I believe the wrong question is being asked, namely, Can we provide FFN? Yes, in most instances of course we can, even if some times it is not positive and may in fact be negative. I think a better more informed question (the one we should be asking) is What is the goal for this patient of administering FFN? (That is, Does administering FFN support the patient's goal[s]?) One size fits one; one sizes rarely fits all.
- While people are relatively willing to withhold the administration of a molecule called oxygen (mechanical ventilation) when the body can no longer take in and/or effectively utilize oxygen, these same people are often unwilling to consider withholding or withdrawing the administration of molecule(s) of food when the body can no longer take in and/or effectively use food. The cultural implications of providing (or not providing food) as a unique measure, set apart somehow as different from other interventions, have far eclipsed the medical implications of the role of food, fluids, and nutrition in maintaining the body.
- While lack of consensus among family members often exists initially when EOL care decisions are required, most of these scenarios can be adequately resolved, utilizing already existing medical, ethical, and legal guidelines via an interdisciplinary team process, including in addition to patient and family, physicians, nurses, spiritual leaders and others.
- The Terri Schiavo scenario was unique (rare) in that the discernment that is often a part of all such scenarios was taken beyond the usual medical, ethical, and legal guidelines to the media and governmental agencies/representatives, where many, some qualified, many not so qualified, and *most without firsthand knowledge* about the specific scenario commented on the scenario or initiated action, based upon partial, incomplete, and/or erroneous information.

GENERAL RESPONSES TO HSB302:

- Iowa's provision for advance directive and power of attorney for health care affairs designations makes it possible for individuals to express their wishes,

eliminating the need for governmental intervention.

- HSB302 creates a process that is not needed to protect vulnerable patients. Medical, ethical, and legal protections already exist. Further, the process created is unduly burdensome to those endeavoring to honor an individual's wishes.
  - This proposal would require all who did not have an advance directive to receive FFN, regardless of other ways in which these individuals may have expressed their values and shared their wishes. This removes patient choice, diminishes respect for patient autonomy, and disregards the critically important role of the individual's family and care givers in such difficult decision making.
  - While many have suggested that these decisions are black or white, yes or no, in actual fact, many of these decisions are not black or white. Rather, the decision is based upon "It depends…. on the individual's unique circumstances." The clinical situations are often too complex to be handled compassionately or effectively via the rigidity of law.

- While the legislation has been in place to implement an advance directive and/or power of attorney for health care affairs, many Iowans have not availed themselves of these avenues of expression. However, many who do NOT have an advance directive have made their wishes known in other ways, to their family members, to their health care providers, and to their spiritual leaders.

  Implementation of the proposed kind of governmental intervention where the incidence of advance directives is very low, i.e. to presume that everyone who does not have an advance directive WANTS artificial nutrition in all circumstances, is simplistic and inadequate to explain and/or honor the desire of the numerous individuals so affected.

- Such a process would be overbearing to health care professionals who diligently strive to discern and honor patient autonomy and individual wishes. In an effort to protect themselves, health care professionals would find this oversite a driving force to "over provide FFN" and in the process the wishes of many would be overridden in the interests of respecting the intent of this law, namely to provide FFN to all who have not made a written declaration to the contrary.

- Implementing this unneeded law as it is proposed would be cumbersome, burdensome, and costly to effectuate. And it would not present future Teri Schiavo cases.

- If the desire is to make improvement in EOL care in Iowa in response to the Terri Schiavo case, the legislature could best accomplish that by providing the necessary funds to educate the public and promote patient-physician discussions on EOL issues and advance directives.

THANK YOU